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ABSTRACT

Data from a mail survey completed by 330 parents of mentally retarded children were analyzed to identify patterns of attributions of causality for the retardation. Results revealed that type of attribution was differentially associated with family background (race), stage at which the child is diagnosed, and utilization of services (extensiveness of physician contact and decision to institutionalize). There was a close correspondence between attributions reported as made by physicians and parents' self reported attributions. (Author)

FAMILY PERCEPTIONS OF RESPONSIBILITY FOR MENTALLY RETARDED CHILDREN*

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ABSTRACT

Five types of attribution of causality for children's mental retardation are identified: iatrogenic, genetic, pragmatic, supernatural, and self-attribution. Data from a mail survey questionnaire, completed by 330 parents, indicates that type of attribution is differentially associated with family background (race), stage at which the child is diagnosed, and utilization of services (extensiveness of physician contact and decision to institutionalize). There is a close correspondence between attributions reported as made by physicians and parents' self-reported attributions.

Family Perceptions of Responsibility for Mentally Retarded Children

Categorizations of ourselves and other's attitudes, feelings and behaviour represents the substance of social scientist' concern with attribution, a phenomenon that lies at the core of our experience as social beings. Attribution, in its most basic form, refers to the way in which individuals explain, account for, or assign responsibility for events.

In answering such questions as "what causes mental retardation?" or "what did we do to deserve a mentally retarded child?" families engage in a "naive analysis of action". Although their approach to such attributional analysis is naive, they operate very much like quasi-scientists in their everyday, commonsense efforts to identify and understand mental retardation. But their identifications of responsibility are not always scientifically objective or rational, may be based on insufficient information, or may be made quickly on inadequate analysis of the information they do have.

Because the general public's experience with mentally retarded persons is very limited, families are not necessarily able to avail themselves of the usual networks of information (i.e., extended family, friends, neighbors) to assist them in understanding and caring for their mentally retarded children. As a result of this information vacuum, the advice of professionals, especially physicians, takes on added weight in families' attribution of responsibility.

Attribution is important because of the need to understand, exercise control over, and predict significant events in our lives (Heider 1958, Kelley 1967). Understanding, control, and prediction are necessary to reduce anxiety and chaos by rendering the environment more stable, predictable, and mangeable. Attribution thus enables families to structure their experiences and permits them to develop expectations about the future that makes it seem less formidable.

The extent to which attribution structures families' behavior with respect to their mentally retarded children is associated with the type of attribution made. There are many competing explanations or world views from which to select (Suelzle, 1977). Explanations accounting for mental retardation include:

1. Iatrogenic Attribution. The medical profession in general or a specific physician may be perceived as responsible for the mental retardation. A physician may accept responsibility for a mistake or the parents may infer blame without confirmation. If a physician is held accountable for a mistake, there may be a greater willingness on the part of the medical profession to accept an ongoing responsibility for the child, including more extensive referrals and even assistance in having the child institutionalized.

2. Genetic Attribution. Attributing the mental retardation to genetic problems provides a technical explanation, usually of an impersonal nature. Whether or not parents blame themselves for their child's condition, they may seek further information about the child's potential for development or about the probability of recurrence should other children be planned.

3. Pragmatic Attribution. Families may simply accept the mental retardation as a random event which could have happened to anybody. Nevertheless there is an element of ambiguity that may mean the attribution of unkown etiology is arrived at after a period of searching for more definitive explanations rather than it being an attribution which is quickly accepted.

4. Supernatural Attribution. Families may psychologically distance themselves from the event by attributing responsibility to an ethereal cause such as the will of God. If responsibility is assigned outside the worldly experience entirely, then a more passive acceptance of the condition would be expected.

5. Self Attribution. Families may blame themselves for the mental retardation, selecting particular behaviors or traits as responsible. For example, the mother might blame herself for smoking, drinking, or a previous abortion, or either parent might blame themselves because of their family background. If the child is a constant reminder of one's own perceived failures, families may be more anxious to institutionalize.

METHODS

Sampling Procedures

The population was defined as Lake County, Illinois, parents of mentally retarded children ages 0 - 21 who receive services in Lake County. For the purposes of the study, mentally retarded children are defined as those whose disability required more than 50 percent time in special education programs. All the children in the study had severe enough forms of mental retardation (with some having cerebral palsy, epilepsy, autism, in addition to mental retardation) that they would be classified in the moderate, severe, or profound ranges.

The area of Lake County was selected for the research population because: (1) it is geographically compact yet includes urban, suburban, and rural populations; (2) it offers a wide variety of services for mentally retarded persons; (3) providers and consumers of services to mentally retarded persons have a history of cooperation with past efforts to secure related information; and (4) the county contains people of a wide range of socioeconomic, ethnic, and racial backgrounds.

Data Collection Procedures

A computerized review of the literature and open-ended depth interviews with parents were used to construct a pretested 57-page mail survey questionnaire. Structured closed-ended questions were designed to provide data regarding: the manner in which parents first discovered that their child was mentally retarded; availability of extended family and community support networks; the severity of the mental retardation; the manner in which parents secure community services; professionals utilized; attitudes regarding direct services; involvement in children's educational programs and parents' organizations; opinions about public policy; and long-term plans and objectives for their children.

Because of adherence to regulations governing rights of privacy, consent forms were sent to 751 identified families through the educational facilities serving the county. After a follow-up mailing to increase consents, questionnaires were mailed out over the three-month period from mid-March to mid-June 1978 to the 458 families (61.0 percent) who consented to participate. Quality control procedures to ensure respondent anonymity were used. A follow-up mailing resulted in the return of 330 completed questionnaires (43.0 percent of the families identified and contacted; 72.1 percent of the families who consented to participate).

Returned questionnaires were coded and keypunched and a file defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. The data was cleaned by eliminating out-of-range errors and performing a series of contingency checks.

Characteristics of Parents and their Children

Although the questionnaires were mailed to both parents in two-parent families, almost all were completed by the children's mothers. Of these mothers, 20 percent had not completed high school, 33 percent were high school graduates, 31 percent had some college or special career training, and 16 percent were college graduates. In 1978 dollars, 33 percent had yearly family incomes before taxes of less than $15,000, 39 percent between $15 - 25,000, and 28 percent over $25,000. The vast majority (86 percent) were currently married; that is, most children in the study were from two-parent homes. About half of the mothers (48 percent) were employed outside the home, a group about equally divided between those holding full-time and part-time jobs. In terms of racial composition, 83 percent of the sample were white, 11 percent black, 3 percent Latino, and 3 percent Asian or American Indian.

In general, our respondents seem to be fairly representative of the Lake County population in terms of range of social and economic characteristics, expect to overrepresent minorities, high school graduates, and single-parent families.

Of the children reported on in the questionnaire, 21 percent were identified by their parents as mildly retarded, 34 percent as moderately mentally retarded, 20 percent as severely and profoundly mentally retarded, 12 percent as having cerebral palsy, 4 percent as autistic, and 9 percent as having epilepsy. Of the children, 57 percent were male and 43 percent were female.

RESULTS

Physicians play an important role in the recognition of mental retardation in children.

The stage at which mental retardation is diagnosed has been hypothesized to be associated with parents' behavior vis-a-vis physicians (MacMillan 1977). The stage at which their children's mental retardation was recognized is quite variable: 26% were recognized prenatally and perinatally, 45% within the first two years, 22% by elementary school age (6 years), and the remaining 7% after the children entered elementary school.

For our population, physicians (such as obstetricians, pediatricians, and family practitioners) were slightly more likely than parents to recognize the children's mental retardation first (42% and 40% respectively, with the remaining 18% being initially recognized by teachers, school psychologists, friends, relatives, nurses, or social workers). When parents realized that their children were mentally retarded, physicians were the professionals most frequently contacted (by 87.0% of families). Nearly one-half of the first physicians contacted made a diagnosis (47%) or referrals to other medical specialists (46%). About one-third provided a prognosis, one-quarter referred parents to available community services, and one-fifth suggested institutionalization.

The types of physicians who examine children for mental retardation vary. Four-fifths of the children in our sample were first examined by pediatricians or family practitioners. In contrast subsequent medical examinations were performed much more frequently by specialists, including special clinics, diag-

nostic or genetic centers (59%) and with neurologists (42%). Pediatricians, however, are almost as highly utilized for second or additional opinions (41%) as for the first examination, whereas general practitioners are not (18%).

Most parents are unprepared for the birth of a child with mental retardation. Approximately two-thirds have no prior familiarity with mental retardation. Information provided by physicians therefore is extremely important in determining the attributions which families make about the cause of the mental retardation. In fact, more than two-thirds (68%) of the parents found at least one physician they consulted did give a prognosis.

More than one-third (34%) of the parents found at least one physician who suggested institutionalization, yet only 15% had children who had been institutionalized. Physicians' recommendations to institutionalize increased with the severity of the mental retardation.

The vast majority of families (84%) had contacted more than one physician. Parents were more likely to change physicians if the children's mental retardation was severe or if their family incomes were higher. About one-third (35%) of parents had changed their children's physicians because of dissatisfaction with the care provided.

Parents Versus Physicians Perceptions of Responsibility

Included in the questionnaire were two parallel sets of questions which enabled us to determine the degree of congruence between attributions reported as made by physicians and parents' self-reported perceptions of responsibility for their children's mental retardation. Out of 12 items listed in each of the

two sets of questions, one item measured each of iatrogenic, genetic, pragmatic, and supernatural attributions. The remaining 8 items measured different aspects of self attribution. (See Table 1.).

Table 1 about here

Parents' reports about perceptions of responsibility were almost identical for physicians and themselves. The two items on which discrepancies were reported measured iatrogenic attribution and supernatural attribution. In the case of iatrogenic attribution, parents were more likely to believe a medical or physician's mistake was responsible than physicians were reported as admitting (17.6 percent vs. 10.4 percent respectively). Similarly in the case of supernatural attribution parents were more likely to believe the mental ratardation occurred due to the will of God than physicians were reported as believing (37.5 percent vs. 18.8 percent respectively.). Of all the items, pragmatic attribution was overwhelmingly the most frequently reported (by 60.4 percent of the families and for 61.8 percent of the physicians). As an indicator of the honesty of the attributions reported, those families making a genetic attribution correspond roughly to the proportion of mental retardation in which the etiology is attributable to identifiable genetic causes (in approximately 2 out 10 cases).

Iatrogenic Attribution

Stage at which the diagnosis took place, whether or not children were institutionalized, and whether or not multiple physicians were consulted, were all significantly associated with iatrogenic attribution (See Table 2). If a medical or physician's mistake was held responsible for the mental retardation, it was more likely the child had been diagnosed postnatally than if a physician

was not held responsible. Conversely, if the diagnosis was made prenatally or perinatally it was less likely a medical or physician's mistake was held responsible. This pattern is consistent with the tendency for mental retardation due to problems during delivery (for example, cerebral palsy, asphyxia) not to become evident until several months after delivery.

Table 2 about here

If a physician is responsible for the mental retardation it logically follows that there would be an increased effort on the part of the medical professionals to alleviate the family's burden of care. Accordingly it was more likely that children would be institutionalized and multiple physicians contacted when a medical or physician's mistake was held responsible. Findings were similar to those for parents' self-reports when iatrogenic attributions reported for physicians were examined (results not reported here). However, when physicians made iatrogenic attributions, an even larger proportion of children were institutionalized (38% institutionalized when physicians were reported as admitting responsibility contrasted to 26% institutionalized when families held the physician responsible).

To test whether type of attribution was associated with families' characteristics, seven demographic variables (family income, race, mother's education, marital status, mother's age, child's sex, severity of child's disability) were tabulated against type of attribution. Only race was significantly associated with any of the types of attribution. Race has been reported for comparative purposes between types, although not associated with iatrogenic attribution.

Genetic Attribution

In the case of genetic attribution children were less likely to have been diagnosed postnatally (i.e., more likely to have been diagnosed prenatally or perinatally) than if no genetic attribution was made (see Table 3). Genetic attribution was not associated with whether or not children were institutionalized, but it was more likely that families would have consulted multiple physicians when genetic problems were acknowledged.

Table 3 about here

Genetic attribution was more prevalent among white families than black families. While our interpretation is at the level of speculation, we believe physicians may be more reluctant to provide genetic explanations to black families given the larger societal controversy concerning the hypothesized genetic inferiority of the black population in general (Jensen 1972).

Pragmatic Attribution

In the case of pragmatic attribution, acceptance of the mental retardation as a random event which could have happened to anyone, as expected there was no association between etiology and either stage at which diagnosis took place or whether children were institutionalized (See Table 4). On the other hand, families were more likely to contact multiple physicians when the etiology was unknown. Such shopping behavior would be expected as a result of families seeking to reduce ambiguity by attempting to obtain a more definitive explanation. We have no interpretation for the finding that unknown etiology is more prevalent among white families than black families.

Table 4 about here

Supernatural Attribution

The case of supernatural attribution, placing responsibility outside the worldly experience of human events, does not impact on actions taken on the children's behalf (See Table 5). That is, holding God's will responsible for mental retardation was not associated with having the child institutionalized or with consulting multiple physicians. Nor was race associated with supernatural attribution. However, families were less likely to make a supernatural attribution if the diagnosis occurred later in the children's lives than if it occurred prenatally or perinatally. That is, God's will is more likely to be held accountable for events up to the moment of birth, whereas human or environmental factors are more likely to be held accountable following birth.

Table 5 about here

Self-Attribution

Self-attribution occurs when mothers blame themselves for their children's mental retardation. As reported in Table 1, this occurred in only a very small proportion of the eight types of events measuring self attribution: mother too old to have had the baby; family history of developmental disabilities; drugs, alcohol, smoking during pregnancy; a fall during pregnancy; did not give the baby enough attention in infancy; mother's diet during pregnancy; negative or ambivalent feelings about having the child; and a previous abortion. Therefore, the eight items were additively combined into a single index of self attribution and then a dummy variable was created. The value for self attribution was set equal to 1 if the respondent reported that any doctor had mentioned at least one of the eight items as possible causes of their children's mental retardation, 0 if otherwise.

In the case of self-attribution, parents were more likely to institutionalize their children if they perceived themselves responsible for their children's retardation (See Table 6). Parents, it would seem, experience more difficulty in keeping their children at home if they personally blame themselves and their children's presence would be a constant reminder of that guilt. Black families were significantly more likely than white families to hold themselves responsible for their children's mental retardation. Black families, may be exposed to situations which place their children at higher risks for mental retardation (for example, black mother's poorer nutrition during pregnancies).

Table 6 about here

CONCLUSIONS

This paper has demonstrated that there are at least five types of attribution which parents make to account for their children's mental retardation. This paper further demonstrates that the types of attributions made are associated with family background (race), whether the diagnosis of mental retardation occurs pre-or perinatally versus post-natally, whether multiple physicians are consulted, and whether or not the child is institutionalized.

The cross-sectional nature of the survey questionnaire employed in this study does not allow us to explore the process of how attribution interacts with family background, timing of the diagnosis, extensiveness of physician consultations, and the decision to institutionalize. Without a longitudinal design, cause-effect relations cannot be measured. The next step would be to undertake a longitudinal design which would allow us to understand the process of attribution and its effects on parents' decision-making in the utilization of services.

Different attributions of causality can be held simultaneously and they may change over the life cycle of the mentally retarded children. It would be important to know how these simultaneous attitudinal structures emerge. For example, type of attributions made could be changed or multiplied as a result of multiple physician contacts, with attendent changes in service utilization. It would also be important to know whether different attributions are of primary, secondary or equal importance in terms of influencing utilizations

of services and outcomes for the children. For example, if a physician is held responsible for the child's mental retardation (Iatrogenic Attribution) it may be more likely that the child may be institutionalized regardless of whether or not other types of attributions are made.

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Table 1. Family Perceptions of Responsibility for Mentally Retarded Children (N=330)

	Physician Mentioned	Family Believes
Iatrogenic attribution: a medical or physician's mistake	10.4%	17.6%
Genetic attribution: genetic problems	20.4%	18.9%
Pragmatic attribution: etiology unknown	61.8%	60.4%
Supernatural attribution: the will of God	18.8%	37.5%
Self attribution:		
Mother too old to have a baby	7.8%	9.6%
Family history of developmental disabilities	7.8%	9.3%
Drugs, alcohol, smoking during pregnancy	3.4%	5.0%
A fall during pregnancy	3.4%	3.7%
Did not give the baby enough attention in infancy	2.2%	1.9%
Mother's diet during pregnancy	1.9%	4.3%
Negative or ambivalent feelings about having the child	1.3%	2.2%
A previous abortion	0.3%	0.9%

Table 2. Percent of Families Perceiving a Medical or Physician's Mistake as Responsible for Children's Mental Retardation (Iatrogenic Attribution)

	Physician Held Responsible (N=57)	Physician Not Held Responsible (N=266)	x^2 1 df
Child diagnosed postnatally	86	73	24.48***
Child institutionalized	26	10	8.62**
Multiple physicians consulted	100	82	10.99***
Race (white)	84	85	.01

** $p \leq .01$

*** $p \leq .001$

Table 3. Percent of Families Acknowledging Genetic Problems as Responsible for Children's Mental Retardation (Genetic Attribution)

	Genetic Problems Acknowledged (N=65)	Genetic Problems Not Acknowledged (N=254)	x^2 1 df
Child diagnosed postnatally	52	80	57.16***
Child institutionalized	9	13	.46
Multiple physicians consulted	95	82	5.96**
Race (white)	94	82	4.23*

*** $p \leq .001$

** $p \leq .01$

* $p \leq .05$

Table 4. Percent of Families Stating Etiology Unknown for Children's Mental Retardation (Pragmatic Attribution)

	Etiology Unknown (N=197)	Etiology Known or Suspected (N=122)	x^2 1 df
Child diagnosed postnatally	73	76	0.75
Child institutionalized	14	10	0.94
Multiple physicians consulted	89	78	6.88**
Race (white)	89	78	5.09*

** $p \leq .01$

* $p \leq .05$

Table 5. Percent of Families Perceiving the Will of God as Responsible for Children's Mental Retardation (Supernatural Attribution)

	God's Will Held Responsible (N=121)	God's Will Not Held Responsible (N=202)	x^2 1 df
Child diagnosed postnatally	64	82	52.12***
Child institutionalized	12	13	.02
Multiple physicians consulted	85	85	0
Race (white)	84	86	.07

*** $p \leq .001$

Table 6. Percent of Families Perceiving Themselves as Responsible for Children's Mental Retardation (Self Attribution)

	Families Held Responsible (N=65)	Families Not Held Responsible (N=265)	x^2 1 df
Child diagnosed postnatally	75	75	0
Child institutionalized	21	10	4.59*
Multiple physicians contacted	17	15	.06
Race (white)	75	87	5.04*

* $p < .05$